Chapter 7

General discussion

The focus of this thesis was to gain insight into the prevalence and identification of physical health problems in adults with SPIMD. Better understanding of the prevalence and identification of physical health problems will help to target proactive prevention and treatment. Additionally, early adequate identification may improve or maintain health as well as enhance the ability to perform daily activities, participate in social activities, and increase the quality of life for this population.

Summary of main findings

Prevalence of physical health problems and patterns in multimorbidity

To determine the prevalence of various types of physical health problems in adults with SPIMD, a systematic literature review and a cross-sectional study of reported physical health problems in medical records and personal support plans were conducted. The systematic review (**Chapter 2**) identified 35 physical health problems in 20 different studies. Most studies focused on a single or a relatively small number of health problems. Meta-analysis could be performed for the prevalence of six health problems, namely, epilepsy (prevalence: 70%; 95% CI 65–75%), pulmonary/respiratory problems (prevalence: 21%; 95% CI 12–30%), hearing problems (prevalence: 21%; 95% C I6–36%), dysphagia (prevalence: 30%; 95% CI 11–50%), reflux disease (prevalence: 16%; 95% CI 2–29%), and visual problems (prevalence: 56%; 95% CI 39–73%). None of the studies focused on the entire range of physical health problems in people with SPIMD. Therefore, the prevalence of the entire range of these problems remained uncertain, hence, the need to gain further knowledge regarding the prevalence of physical health problems in this population.

The cross-sectional study **(Chapter 3)** was based on a sample of 99 medical records and care plans of adults with SPIMD. The results show that the most prevalent physical health problems in people with SPIMD include: constipation, visual impairment, epilepsy, spasticity (prevalence more than 75%); deformations, incontinence, gastro-oesophageal reflux (prevalence 50% to75%); and impacted cerumen, dysphagia, deformity foot, contracture, eczema/dermatitis, menstruation problems, pneumonia, and mycoses (prevalence 25% to 50%). The mean number of reported physical health problems was 12 per person, ranging from five to 21. The study also reveals that adults with SIPMD simultaneously experience numerous serious physical health problems.

To explore patterns of multimorbidity in adults with SPIMD, additional data analyses were performed to determine which physical health problems tend to occur together (**Chapter 4).** The results show that the most common combination of two physical health problems comprise the most prevalent problems which included visual impairment, constipation, epilepsy, spasticity, and scoliosis. These five physical health problems occurred as a combination in 37% of the participants. Moreover, in 56% of the participants, a combination of four health problems emerged, namely, constipation, visual impairment, epilepsy, and spasticity. The results indicate that people with SPIMD have complex and interrelated health problems. As a consequence, a broad variety of potential interactions between physical health problems and their treatments may occur.

Identification of physical health problems

To accurately identify a physical health problem, the measurement method must be reliable and valid. To review the reliability and validity of measurement methods that are being used in current practice for identifying physical health problems in adults with SPIMD, an inventory study in current practice and a review in the literature was conducted (**Chapter 5).** In the inventory study, nine standardized measurement methods were reported: the Bristol Stool Form Scale, ear and rectal thermometer, the 'Signaleringslijst Verslikken' (Dutch Screening tool for Dysphagia) in adults with ID, manual and automated sphygmomanometer, pulse oximeter, bladder scan, and the Barnes Akathisia Rating Scale. Subsequently, these measurement methods were reviewed in the literature. No studies were found regarding the validity and reliability for the use of these measurement methods in people with ID/SPIMD. In the non-ID population, only the rectal thermometer and the Bladderscan were sufficiently reliable and valid. The results indicate that there is a significant gap in scientific evidence regarding the reliability and validity of measurement methods that are used in current practice for identifying physical health problems in adults with SPIMD.

In the Netherlands, direct support staff use a screening questionnaire, the 'Signaleringslijst Verslikken' (SV), for the identification of dysphagia in people with SPIMD. However, neither the reliability nor the validity of the SV within this specific population were determined. To examine the convergent validity of the questionnaire, the results of the SV were compared with results of a reference test: Dysphagia Disorders Survey (DDS) (**Chapter 6).** The SV was developed to be an easy-to-use tool for direct support staff to screen for dysphagia in people with ID aged 50 years and older. The proportion of agreement between the SV and the DDS was 0.59. The SV appeared to be inaccurate in the range mild to moderate dysphagia. The results of the study show that the SV is not valid for detecting the presence of dysphagia in people with SPIMD. Relying upon direct support staff to screen for the presence of dysphagia with the SV in this particular group is an unnecessary step and a risk factor for under recognition of dysphagia. All people with SPIMD aged 50 years and older should be assessed for dysphagia by swallowing specialists such as speech and language therapists or by a multidisciplinary dysphagia team.

Methodological considerations

The data in this thesis relate to adults with SPIMD who receive care and support in residential facilities. Most of the participants in the study in this thesis received medical care from physicians/nurses who are specialized in health care for people with ID. Living arrangements and health services for adults with SPIMD may be different across different countries. In the Netherlands, most adults with severe or profound ID (93%) receive care and support in residential facilities (NVAVG, 2012). Therefore, the findings of the studies in this thesis may be less representative for individuals with SPIMD living in more community-based settings and who may have less contact with healthcare practitioners.

Both the studies of the estimated prevalence of physical health problems and the exploration of patterns of multimorbidity were based on data obtained from medical records and care plans. Relying on data from records has several limitations. The quality of the data depends on the accuracy of the documentation: what can be collected from records is limited by what they contain. Incomplete or poor documentation can affect the reliability of the data that is abstracted. However, the use of two data sources, i.e., medical records and care plans, provided more accurate and complete information. The reliance on reports may have resulted in an underestimation of the prevalence of physical health problems with less visible signs and symptoms. Diagnoses are frequently missed or delayed because of the complex characteristics of the health problems as well as of the person with SPIMD themselves (Suman, 2016). It is evident that a physical assessment, medical examinations, and tests would help to identify more health issues and in an earlier stage. Establishing whether or not under-reporting occurs, will be an important task for future research and requires a more in-depth study with extensive health screening such as a physical examination, laboratory assessment, and swallowing observations. Another disadvantage of utilizing medical records and care plans is that it is not clear which assessments or instruments were used to diagnose the health problems and, therefore, it is unknown if these measurements were valid and reliable.

Discussion of main findings and recommendations for future research

Adults with SPIMD encounter numerous serious physical health problems. These physical health problems can cause distress, particularly in people who lack verbal communication skills. In the general population, the identification of physical health problems with less visible signs and symptoms rely on subjective reporting of symptoms. People with SPIMD cannot verbally express that they are feeling unwell, therefore, direct support staff must be aware of how an individual communicates the presence of distress. They have to know the person well to notice (subtle) changes in behavior, function, or abilities (Heslop et al, 2013). The main change due to distress may only be a reduction or an increase in activity. These changes are important because a reduction in activity, such as withdrawn behavior, may be misinterpreted as being content while an increase in activity may be mistaken as challenging behavior (Regnard et al., 2007). Failing to recognize physical health problems may be due to 'diagnostic overshadowing' such as misattributing symptoms of distress to behavioural problems or as being part of the person's intellectual disabilities (Emerson & Baines, 2011). An observation checklist such as the Disability Distress Assessment Tool (DisDAT) may help to identify changes early in behavior, posture, and expression in people with severe communication difficulties. The DisDAT documents a wide range of signs and behaviors in both content and distressed states which allows for monitoring any changes in distress. Cues such as posture, body movements, facial expression, eye appearance, vocal sounds, pulse rate, breathing, sleeping, appetite, and eating patterns are included. However, further research is needed in order to evaluate whether this method is appropriate for direct support staff to recognize and monitor distress in people with SPIMD (Coiffait & Leedham, 2016).

Because of the serious consequences of physical health problems in persons with SPIMD, it is essential that the presence of such a problem is considered when one of these individuals presents with distress or challenging behaviour. However, some of the direct support staff lack knowledge and skills in (early) identification of physical health problems (Suman, 2016; Trollor, Srasuebkul, Xu, & Howlett, 2017). To optimize physical health in people with SPIMD, all direct support staff should have knowledge of physical health problems and should be well trained in early identification of them. Moreover, because all adults with SPIMD simultaneously encounter numerous health problems, it is essential that direct support staff understands how physical health problems and their treatments interact. Understanding common multimorbidity combinations will assist in better recognition of associated physical health problems. Organizations should ensure direct support staff is competent to undertake the task being requested of them. In the Netherlands, professional carers for people with ID have varying backgrounds: the large majority are social workers followed by registered nurses (RNs) and certified nursing assistants (CNAs) (Van der Windt, Smeets, & Arnold, 2009). People with SPIMD require direct support staff with specialised knowledge of their physical health needs. One fundamental way is to focus on improving education (Trollor et al., 2016). In addition, there is a strong need for comprehensive epidemiological data in order to determine patterns of health problems that are specific to people with SPIMD. Therefore, longitudinal data collection or monitoring is recommended to further explore the associations between specific health problems. Additional common combinations of physical health problems may be found in international studies with larger samples.

To timely identify and monitor physical health problems, considerable care must be taken to ensure that the best possible measurement methods are used. The quality of care depends on the validity and reliability of the measurement methods. However, measurement methods used in current practice for the identification of physical health problems in people with SPIMD have no scientific evidence-base, as is shown by the results in this thesis. It is concerning to note that commonly used measurement methods appear not to have been assessed for validity and reliability within this specific population. The field is still much practice-based, and/or the existing evidence is too recent (Suman, 2013). The need for proactive working such as accurate monitoring and reporting of constipation and epilepsy, a proper evaluation of dysphagia, and early detection of secondary complications such as respiratory infections is evident. The challenge of identifying physical health problems includes the use of appropriate measurement methods. A strong evidence-base should make direct support staff more capable to accurately identify physical problems in people with SPIMD. Therefore, further research is needed to enhance the underlying evidence base regarding existing applicable measurement methods and for the development and evaluation of specific measurement methods to identify the physical health problems in people with SPIMD. The results reported in this thesis can provide a preliminary base for determining which measurement method to identify physical health problems should be developed and/or

evaluated. Moreover, we must find ways to improve the sharing and application of knowledge regarding the identification of physical health problems in people with SPIMD.

Implications and recommendations for clinical practice

The focus of this thesis is the physical health of adults with SPIMD. However, it is necessary to bear in mind that the definition of health of the WHO acknowledges that there are three dimensions of health; physical, mental, and social. Mental health problems and social circumstances can also affect the person's wellbeing. The underlying cause of distress can include many factors including physical and mental health problems, adverse effects of medication, and social circumstances (Simpson, Mizen, & Cooper, 2016). Organizations should ensure that direct support staff have the knowledge and skills to contribute to the physical, mental, and social well-being of people with SPIMD and to obtain thorough medical and personal histories. Social workers receive limited training in relation to health issues, and health professionals have limited expertise in the socio-psychological needs of the people being supported. In practice, multiple health workers from different professional backgrounds must collaborate to deliver the highest quality of care (WHO, 2010). To meet the complex health needs of people with SPIMD, a holistic approach is needed with continuous collaboration between professionals (Marengoni et al., 2011). To build such a workforce, joint education for healthcare professionals supporting this population is necessary.

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